

HOW TO ORGANIZE A NURSING HOME ADVOCACY GROUP

Developed by: California Advocates for Nursing Home Reform.
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I. How To Set Up The Organization

A. Structure:

1. Goals and Purposes of the Organization: Develop the goals and purposes of the organization. Both long term goals (e.g., improving the quality of care in nursing homes), and specific short term goals (e.g., providing education to families and friends of nursing home residents; organizing family councils, etc.) should be developed. Preparing a formal, written document will help, not only in formulating the goals, but in community outreach.

2. Advisory Committee: An Advisory Committee can be extremely helpful at the start-up stage of any organization. While many prominent people may not have the time to participate in an active way with the organization, they might lend their names to the organization's letterhead and may be available to lend advice. Local or state politicians, well known community activists, or other prominent persons can be approached to lend their support (and names) to an advisory committee and the organization's letterhead.

3. Incorporation: Formal bylaws and articles of incorporation should be prepared. There are a number of self-help books on how to incorporate. Most major bookstores have a legal section where you can find a book on how to incorporate a not-for-profit in your state. These books usually include sample bylaws, sample articles of incorporation, etc., and the addresses and phone numbers of the applicable state and federal agencies. Application for tax-exempt status with the state and with the Internal Revenue Service should be made. While it is not essential that your organization be incorporated, if you anticipate applying for foundation grants or soliciting contributions, it is usually required that you be a 501(c)(3) organization.

4. Board of Directors: Check your state corporation laws to find out the minimum number of directors required. Since the primary purpose of the Board is to set the policy of the organization and to assist in funding development, these considerations should be kept in mind when approaching potential board members.

You should not have to spend a lot of time educating board members as to the need for the organization. People who are sensitive to the problems in nursing homes, knowledgeable about the issues, and/or have expertise in the funding arena are good candidates.

B. Do Your Homework:

Familiarize yourselves with the state and federal regulations and laws regarding nursing homes, the state reimbursement process, enforcement system, and who's who in the state regarding nursing homes. These include the enforcement agencies, nursing home associations, legislators who have carried reform legislation or who have carried legislation for the nursing home industry, the major nursing home chains in your state, etc. Only when you know the players involved in the game and the rules by which they have been playing will you be able to participate and change the rules.

C. Initial Funding:

Since it can take 3-6 months to receive formal notice of non-profit status, some initial funding might be required for start up. A local foundation might be approached for seed money, which can be given to a "fiscal intermediary" for your start up. A few individuals might also be willing to give initial contributions (\$2,000-3,000) for a small office, printing letterhead, phone, etc., until the organization can get an initial grant. Brochures should be printed and, if funds allow, an initial mail solicitation can generate funds and a list of potential active members.

II. Outreach

A. Media: Local media, print and electronic, should be approached for public service announcements about your organization, potential articles about the problems in nursing homes, radio/TV talk shows highlighting your organization, etc. This can generate on-going media contacts and public awareness of your organization. Remember that the media always wants to talk to real people who have had real problems with care.

B. Families/Friends of Nursing Home Residents: Can be invited to a forum on nursing home issues. On-going Family Support Groups can be a focus of the meeting. Such groups can educate relatives as to their rights, the rights of the residents, legal and financial concerns, how to file a complaint, etc. Speakers from local community organizations can be recruited to participate.

C. Family & Residents' Councils: Offer your organization's services to speak at local facility family and/or residents' councils. This will afford you the opportunity to educate consumers and to generate support for your organization.

D. Networking: Reach out to other community health organizations or senior organizations. Co-sponsor workshops, initiate regular meetings with the local ombudsman, co-sponsor family support groups, etc.

III. Ongoing Funding:

Funding, or the lack thereof, can make or break your organization. A source of on-going funding is essential if you want to continue to operate. Familiarize yourselves with the way that other non-profits operate, particularly those that do not receive government support. There are a

number of ways to generate income for the organization, while avoiding bake sales. These are a few that we have identified:

A. Foundation grants: Local foundations give grants to nonprofit organizations that meet their criteria. Find out which foundations might be interested in funding your organization, call or write for application, prepare an annual budget, apply. Note that most foundations require proof of IRS non-profit status.

B. Membership dues: A membership-based organization can generate an annual source of income, e.g., \$20 per year in dues can pay for postage and printing of a quarterly newsletter. This does not necessarily mean a "formal" membership organization, where the members vote for the Board or make policy decisions. You can solicit "Associate" members, who receive a membership card and a subscription to the newsletter.

C. Fee for Services: Charging \$10 or more for workshops on special areas such as Medicaid eligibility or spousal impoverishment, when a spouse enters a nursing home or providing continuing education training to social workers and discharge planners.

D. Special events: An annual "advocacy awards" dinner or luncheon, or an auction with donations of goods and services from the community can raise funds and the public awareness of your group.

IV. **Projects/Services:**

In deciding what projects or services your organization will develop, keep in mind your original goals and purposes. It is too easy to get lost in the day to day operations of answering calls and questions that perhaps should be answered by other organizations. Remember that you are an "advocacy" organization and your projects should reflect your goals. This can include any number of activities such as:

A. Organizing Regional Family Support Groups and individual family councils in specific nursing homes.

B. Forming a consumer work group that meets regularly with the state and local licensing and enforcement agencies to discuss changes in policies.

C. Monitoring local and/or state nursing homes and focusing media attention on problem facilities.

D. Preparing special handouts on how to organize family councils, how to file a complaint, residents' rights, etc.

E. Monitoring state legislation or lobbying your own legislation. (Note IRS restrictions on lobbying activities)

F. Picketing problem nursing homes.

G. Organize, educate, speak out until changes are made.

V. Lobbying Activities

Most nursing home advocacy organizations want to change their state laws or create new laws that increase residents' rights protections. In other words, they want to lobby their state legislators. A section 501(c)(3) organization *may* attempt to influence legislation, but only as an *insubstantial* part of its activities. Activities to support or oppose political candidates are completely forbidden for such organizations, however. The issue for most not for profits who would like to engage in some lobbying is the definition of "substantial part." You should speak to a qualified non-profit tax specialist in your area to discuss your options regarding lobbying activities and IRS reporting requirements. For example, certain eligible 501(c)(3) organizations may opt to file a Form 5768, which allows them to use an alternative "expenditures" test and limits their lobbying to a certain percentage of their budgets. There are several options for non-profits, but these should be discussed with someone qualified in IRS non-profit laws.

We wish you luck in your project. You are always welcome to call the CANHR office for further information: (415) 974-5171. Or visit CANHR's web site at www.canhr.org.

METHODS OF SUPPORTING NURSING HOME REFORM ACTIVITIES:

1. Write letters of support for nursing home reform legislation. Call the CANHR office (415) 474-5171 or visit: www.canhr.org/legislation for list of current pending legislation.
2. Start a local family support group in your area from relatives and friends of nursing home residents. Have invited speakers address the group about issues of concern, e.g., Medi-Cal eligibility (staff from local Medi-Cal office); patient's rights (rep. from local ombudsman office); how to file a complaint (rep. from the local district office of licensing and certification); invite a representative from CANHR to address your group.
3. Organize a family council in your nursing home. Contact CANHR for a "How to organize a family council" packet (FREE). Remember: under state law, family members of nursing home residents must be invited to attend all resident's council meetings. This is one way to get involved and to find out the residents' needs. In addition, federal and state laws regulate family councils in nursing homes. Contact CANHR for assistance.
4. Join CANHR's "Media Watch" campaign. Send clippings regarding nursing home issues to the CANHR office at 650 Harrison Street, 2nd Floor, San Francisco, CA 94107. If you have a story that should be exposed, send a notice to the media, or send it to us.
5. File complaints with the local District Office of Licensing & Certification. The LCD office is only required to visit nursing homes once a year. However, they will also visit in response to legitimate complaints. Make sure your complaint is in writing, and notes the time, date, place, and facts. The complainant has a right to accompany the surveyor on the facility inspection and to appeal if you don't think the results are satisfactory. Send a copy of your complaint to CANHR. Always send a copy to your local ombudsman program and ask them to assist you in resolving the complaint.
6. Contribute financially. CANHR is supported primarily by contributions and foundation grants. If you are financially able, send a contribution to CANHR and ask your friends to support CANHR's work. Membership in CANHR (\$30/year) includes a free subscription to CANHR's newsletter.